

Pacific West Distance Learning Network Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Care Module Objectives and Activities

Learning Objectives

After completing the module, the participant will have the knowledge and skills to:

1. Describe the elements of family-centered care and provide examples of each
2. Identify methods of communication with family members and other care providers that include the family as a team member in developing an individual's nutrition care plan
3. Identify appropriate language that reflects family-centered principles
4. Identify service policies and procedures that encourage active inclusion of families in planning nutrition interventions and services

Outline of Activities


- Introduction to the module
- Review handout packet materials with the group leader
 - Learning objectives and outline of activities (this page)
 - PowerPoint slide handout
 - "Welcome to Holland" Essay
 - "It Makes You Think Harder" Sibling Perspective
 - 8 Elements of Family-Centered Care
 - 7 Characteristics of Family-Professional Collaboration
 - Resource list
 - For families
 - For professionals
 - Post-test
 - Evaluation form
 - Certificate of completion
 - State nutrition services list
- Presentation
 - A. Video: Family-Centered Care
 - B. Powerpoint presentation: including case studies
 1. Harold
 2. Martina
 - C. Discuss the essay "Welcome to Holland" (optional)
- Post-test and evaluation forms
- Evaluation forms are exchanged for completion certificates
- Thank you for participating!

Pacific West Distance Learning Network Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services Presentation Notes

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Nutrition for Children with Special Health Care Needs
Module 1: Providing Family-Centered Services



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**Pacific West MCH
Distance-Learning Curricula**

- Nutrition for Children with Special Health Care Needs - 6 self-study modules
- Nutrition for Children with Special Health Care Needs - 4 group study modules (this presentation is one of them)
- Nutrition and Oral Health Curriculum

all available (free) on-line at
www.pacificwestmch.org

Interdisciplinary Approach to Feeding




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Group Study Curriculum

Module 1: Providing Family-Centered Care
Module 2: Participating in the Interdisciplinary Approach to Feeding Interventions
Module 3: State and Local Nutrition Resources
Module 4: Improving Nutrition Interventions

Interdisciplinary Approach to Feeding



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Learning Objectives

After completing the module, participants will have the knowledge and skills to:

- Describe the elements of family-centered care and provide examples
- Identify methods of communication that include the family as a team member in developing an individual's nutrition care plan
- Identify language that reflects family-centered principles
- Identify policies and procedures that encourage active inclusion of families



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Family-centered Care

“Family-centered care is an approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial **partnerships between health care providers, patients, and families.**”

<http://www.familycenteredcare.org>




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Family-centered Care


- “Family” – two or more persons who are related in any way: biologically, emotionally, legally
- Family-centered vs. Patient-centered – pediatric vs. adult care
- Family-centered vs. Family-focused – collaborative vs. expert and “unit of intervention”




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Video: Family-Centered Care


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Language...how are your words interpreted?

- “Family unavailable for interview”
- “Compliance is poor”
- “Presented the Chinese food summary, but dad claims the suggestions don’t apply”
- “One of my cases is a 5-year old Down’s kid”

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Family-centered Language

“...When we recognize that people with disabilities are people first, we can begin to see how people with disabilities are more like people without disabilities than they are different.”

Kathie Snow, 1998

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Family-centered Language: "People-first language"

- Focus on the individual, not the disability; do not refer to the disability unless it's relevant
- Avoid labeling people: "a Down's kid" vs. "a child who has Down syndrome"
- Emphasize abilities not limitations: "confined to a wheelchair" vs. "uses a wheelchair"
- Avoid negative or sensational descriptions (achieved a near-normal life despite suffering from...)
- Avoid using "normal" to describe people without disabilities



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People-first Language

Change the following from "language to avoid" to "people-first language"

- the handicapped
- normal kid
- he is autistic
- he's one of my cases
- a quadriplegic
- she is learning disabled
- a victim of epilepsy



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HIPPA and the Privacy Rule

Guidelines for protection of patient privacy and information management:


- The Health Insurance Portability and Accountability Act of 1996 (HIPAA)
- Department of Health and Human Service's "Standards for Privacy of Individually Identifiable Health Information" regulation (Privacy Rule)




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 **HIPPA and the Privacy Rule**

- Patients must have access to their medical information
- A written consent must be completed before medical information is released
- More information:
 - <http://www.hhs.gov/ocr/hipaa>
 - <http://aspe.hhs.gov/admsimp>


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 **Barriers to Family-centered Care**

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 **Case Study 1: Harold**

- Harold is a 5 year old who requires a g-tube to meet his nutrient needs
- Was tolerating the standard pediatric formula
- Family began making blenderized formula (formula, whole milk, vegetables, egg) because they wanted to provide “real food.”
- RD told family: Harold’s nutrient needs are being met by his formula, and he doesn’t need the extra food. You should just use the prescribed formula.

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Case Study 1: What went right?



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Case Study 1: What went wrong?



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Case Study 1: Harold



RD realizes need for collaboration, and explains concerns about the homemade formula:

- raw egg is unsafe
- nutrient composition may not meet needs
- can have problems with contamination
- can have problems with tube clogging because of viscosity of formula

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Case Study 1: Harold

Harold's parents would like to use the home-prepared formula, if possible. RD works with family to make it possible:

- Raw egg is unsafe; they agree to stop using it
- Recipe is adjusted to meet Harold's nutrient needs
- Family will watch for clogging problems and communicate them to RD



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Case Study 2: Martina

- Martina is a 2 year old with a rare disorder
- Clinician thought that Martina's family would benefit from the support that a mentor family could provide
- Clinician asked a mentor family to contact Martina's family



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Case Study 2: What went right?



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Case Study 2: What went wrong?



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Case Study 2: Martina



- Martina's family was upset by the unsolicited phone call
- The clinician decided to implement a new policy:
 - Offer phone call from mentor family
 - If call is accepted, obtain signed release of information
 - If call is declined, offer at a subsequent visit

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Further thought...



- Give an example of a time you practiced family-centered care
- Give an example of care you've received that was not family-centered...what could the clinician have done differently?
- How can you improve your practice?

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Group Study Module 1: Providing Family-Centered Services

Welcome to Holland

The experience of raising a handicapped child feels like this...

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guide books and make your wonderful plans; The Coliseum, Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"HOLLAND?!?" you say. "What do you mean, Holland? I signed up for Italy? I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there's been a change in flight plans. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you just go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for awhile and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips and Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I planned."

And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Emily Perl Kingsley

Ms. Kingsley is the mother of Jason, who has Down syndrome. She is a frequent lecturer on mental retardation and disability rights. Ms. Kingsley has also received 12 Emmy Awards and 9 Emmy nominations for her work on *Sesame Street*.

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Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services

“It Makes You Think Harder” *Philip Lanier, Age 8*

April 29, 1989

What is it like to be the brother of a MPS child?

“It’s funny

Like when Matthew bangs his head on the floor or pours himself some milk and it goes all over the floor.

It’s disappointing

Like when he gets into my drawers.

It’s boring

Like when I had chicken pox and had to stay in my room.*

It’s fun

Like when Andrew won’t wrestle with me and Matthew will.

It makes you strong

Like when you have to lift him.

It makes you think harder

Like when the thing broke on the gate and I put a rock on both sides to hold the gate so Matthew couldn’t get out.”

* In January 1989, Matt came home from the hospital with his brother Andrew’s bone marrow. Matt was, of course, immunosuppressed and we were warned to avoid chicken pox. Both of Matt’s brothers came down with chicken pox within a couple of weeks of Matt coming home. Thus we tried to isolate the brothers from him by keeping them in their bedrooms during the contagious phase of the disease. Matthew never did get chicken pox—even though he found and used Philip’s toothbrush!

Pacific West Distance Learning Network Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services Elements of Family-Centered Care

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
2. Facilitation of parent/professional collaboration at all levels of health care: care of an individual child; program development, implementation, and evaluation; and policy formation.
3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
5. Recognition of family strengths and individuality and respect for different methods of coping.
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems.
7. Encouragement and facilitation of parent-to-parent support.
8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.

Shelton TL, Jeppson ES, and Johnson BH. (1987). Family-centered care for children with special health care needs. Washington, D.C.: Association for the Care of Children's Health.

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Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services
7 Characteristics of Family/Professional Collaboration

A truly collaborative family/professional relationship:

1. promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family;
2. recognizes and respects the knowledge, skills and experience that families and professionals bring to the relationship;
3. acknowledges that the development of trust is an integral part of a collaborative relationship;
4. facilitates open communication so that families and professionals feel free to express themselves;
5. creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored;
6. recognizes that negotiation is essential in a collaborative relationship; and
7. brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health needs and their families.

Bishop K, Woll J, Arango P. (1993). Family/Professional Collaboration for Children with Special Health Needs and Their Families.

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Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services

Resources for Families

Books

1. After the Tears: Parents Talk About Raising a Child with a Disability. Edited by Robin Simons
2. You Will Dream New Dreams: Inspiring personal stories by parents of children with disabilities by Stanley D. Klein and Kim Schive
3. Meeting the Challenge of Disability or Chronic Illness—A Family Guide by Goldfarb, Brotherson, Summers and Turnbull
4. Nobody's Perfect by Nancy B. Miller
5. No Pity by Joseph Shapiro (written with the person with the disability point of view; includes history of disability movement)
6. Claiming Disability by Simi Linton (written with the person with the disability point of view)
7. The Care Notebook This is an organizational tool for families to keep medical information, etc., in one place. Available free for Washington families; at cost for families outside Washington. Moore Business Forms and Business Division 206-689-2900 or can be downloaded from CHRMC website (<http://www.seattlechildrens.org/parents/special/notebook.htm>)
8. The Starting Point A guide for Washington State families that provides a brief family-friendly overview of resources available for families of children with special health needs. Available n-line: <http://www.seattlechildrens.org/parents/special/resource.htm>
9. Speak Up for Health: A Handbook for Parents of Teens with Chronic Illness or Disabilities Available from PACER Center, Inc. 612-827-2966.
10. Living Your Own Life: A handbook for teenagers by teenagers with chronic illness or disabilities Available from PACER Center, Inc., 612-827-2966.

Magazines, Articles, Handouts

1. Exceptional Parent This magazine provides information and support for the special needs community—parents-families-physicians-professionals. 877-372-7368
2. Linkages This is a Washington state quarterly newsletter sharing information, updates and resources for professionals and families caring for children with special needs. Available on-line: <http://www.cshcn.org/resources/resources.htm>
3. Welcome to Holland by Emily Perl Kingsley
4. You Are Not Alone: For Parents When They Learn That Their Child Has a Disability by Patty McGill Smith. This article, written for the National Information Center for Children and Youth with Disabilities (NICHCY), is available on-line: <http://www.nichcy.org/pubs/newsdig/nd20txt.htm>
5. It Makes You Think Harder by Philip Lanier
6. Images of Fathers by James May. This article is available on-line at the Fathers Network website: <http://www.fathersnetwork.org/page.php?page=654&>
7. My Teacher by Clarence Burris. This article is available on-line at the Fathers Network website: <http://www.fathersnetwork.org/page.php?page=623&>
8. It's the 'Person First' Then the Disability by PACER Center, 2000. This document is available from the PACER Center (<http://www.pacer.org>); Item No. PHP-C31 and is also available on-line at: <http://www.directionservice.org/PersonFirst.pdf>

Web Sites

Family Voices <http://www.familyvoices.org>

Family Voices works toward addressing the common challenges that all children with special health care needs face. Their advocacy efforts revolve around three basic principles that the organization believes should be part of health care reform: family-centered care, community-based services, and parent-professional collaboration. The site serves as a national clearinghouse for information and resources.

Family Village http://www.family_village.wisc.edu

This easy to navigate site describes itself as a global community on the Internet for families of persons who have disabilities. It has a wealth of information, resources, and web site connections for people with disabilities and their families and service providers.

National Fathers' Network <http://www.fathersnetwork.org>

This organization focuses on providing resources and support for fathers of children who have special health care needs. The site has an online newsletter, lists of programs, information and resources for fathers, and links to other related sites. One section that shouldn't be missed is the photo album containing photos and stories told by fathers and children. Many articles are in Spanish.

The National Information Center for Children and Youth with Disabilities (NICHCY) <http://www.nichcy.org>

This agency is a national information and referral center that provides information on disabilities and disability-related issues. The site allows visitors access to fact sheets, resources and parent guides, bibliographies, and issue papers. It also offers a comprehensive list of state organizations concerned with disability issues and information searches of NICHCY's database.

The Sibling Support Project <http://seattlechildrens.org/sibsupp/>

The Sibling Support Project is a national program dedicated to the interests of brothers and sisters of people with special health and developmental needs. It is based at Children's Hospital and Regional Medical Center in Seattle, WA.

Parent Training and Information Centers <http://familyvillage.wisc.edu/education/pti.htm>

Every state has one and sometimes more than one parent training and information center. These centers are funded by the federal government and exist to train and educate parents about laws governing special education. They usually provide advocacy around education issues.

Parent to Parent Programs http://familyvillage.wisc.edu/cof_p2p/htm

These programs provide emotional support and parent to parent matching, as well as referral to resources. Other forms of connections for families (such as listservs, chat rooms) may be explored at the Family Village site at <http://familyvillage.wisc.edu/education/pt.html>

Please note that the Washington Parent to Parent link is incorrect. The correct link is <http://arcwa.com/parent2.htm>

The ARC of the United States <http://www.thearc.org/>

The national organization of and for people with mental retardation and related developmental disabilities and their families.

The Arc of WA State <http://arcwa.com/>

Since 1936, the Arc of Washington State has been a leader in the development of services and programs for people with developmental disabilities, such as autism, cerebral palsy, mental retardation,

epilepsy and related neurological disorders which occur before age 18. The Arc of WA State, a non-profit organization, is affiliated with The Arc of the United States and eleven local Arc chapters throughout the state. The mission of The Arc of Washington State is to promote the education, health, self-sufficiency, self-advocacy, inclusion and choices of individuals with developmental disabilities and their families. (Link at this site to Parent-to-Parent programs in Washington State.)

American Association of University Centers on Disabilities (AUCD) <http://www.aucd.org>

University Centers on Disabilities (formerly University Affiliated Programs) target and engage in activities to support the independence, productivity, integration, and inclusion of persons with developmental disabilities into the community. This site contains a program contact list by state.

Seattle Children's Hospital and Regional Medical Center <http://seattlechildrens.org>

This site represents Children's Hospital and Regional Medical Center in Seattle. It has a section under Parents, Children, and Families entitled "Children with Special Needs" that has many useful resources, including the Care Notebook.

Adolescent Health Transition Project <http://depts.washington.edu/healthtr>

This site is a resource for health care providers and educators, for parents and families, and for teens and young adults with special health care needs and disabilities about health care transition. Information, issues, and materials are presented, as well as useful links relevant to health care transition and transition in general.

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Group Study Module 1: Providing Family-Centered Services Resources for Professionals

Articles

Bishop KK, Woll J, Arango P. *Family/Professional Collaboration for Children with Special Health Care Needs and Their Families*. 1993. Department of Social Work, University of Vermont. This 48-page document describes the seven principles of family/professional partnerships. Available from the Available through the HRSA Information Center Clearinghouse: www.ask.hrsa.gov Inventory Code: MCHG017.

Brewer EJ, McPherson M, Magrab PR, Hutchins VL. Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics*, 83(6): 1055-1060; 1989.

Websites

Institute for Family-Centered Care www.familycenteredcare.org This non-profit organization is a resource for policy makers, administrators, program planners, direct service providers, educators, and family members. The website includes information about resources related to family-centered care, including publications and videos, newsletters, seminars, and presentations. The website also features a bulletin board to promote discussion about issues related to family-centered care.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Department of Health and Human Service's "Standards for Privacy of Individually Identifiable Health Information" regulation (Privacy Rule <http://www.hhs.gov/ocr/hippa> and <http://aspe.hhs.gov/adminsimp>)

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Group Study Module 1: Providing Family-Centered Services

Post Test

1. Which of the following descriptions is most “family-centered?”
 - a) Down’s kid
 - b) Down Syndrome patient
 - c) child with Down Syndrome
 - d) case with Down Syndrome

2. Which of the following practices is most “family-centered?”
 - a) providing information about all available treatment options
 - b) providing information about the professional’s selection of best possible treatments
 - c) referring the family to another family who has a child with a similar condition
 - d) encouraging the family to research treatment options

3. Which of the following is NOT a principle tenet of family-centered care?
 - a) Facilitation of family/professional collaboration at all levels of health care
 - b) incorporating the developmental needs of children and adolescents into health care delivery systems
 - c) implementing policies that promote providing emotional and financial support to meet the needs of families
 - d) requiring a commitment on the part of the family to participate in the team process

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Group Study Module 1: Providing Family-Centered Services Evaluation

Format and Design	Strongly Agree				Strongly Disagree
The written materials supported the presentation well	5	4	3	2	1
The group dynamic helped me to absorb the content	5	4	3	2	1
The PowerPoint presentation was helpful to my understanding	5	4	3	2	1
The way the materials were organized made sense to me	5	4	3	2	1
The format enhanced my understanding of the content.	5	4	3	2	1
The speaker/lecturer delivered the content well	5	4	3	2	1

What organization or format changes would have improved this presentation?

Content	Strongly Agree				Strongly Disagree
The materials covered met the stated objectives	5	4	3	2	1
What I learned today is relevant to my clinical practice	5	4	3	2	1
The clinical examples provided were					
• consistent with what a clinician might encounter in practice	5	4	3	2	1
• illustrated the points presented in the module	5	4	3	2	1
Effect on Practice					
I can think of recent instances where this information would have been useful to my clinical practice	5	4	3	2	1
I plan to use this resource in my practice	5	4	3	2	1
I would recommend this curriculum to my peers	5	4	3	2	1

What organization or format changes would have improved this presentation?

Please describe one aspect that, if changed, would improve the program:

Overall comments:

What is your discipline or area of expertise?

- | | | |
|--|---|---|
| <input type="checkbox"/> Early Intervention | <input type="checkbox"/> Health Education | <input type="checkbox"/> Parent/ Family/ Consumer Resources |
| <input type="checkbox"/> Education | <input type="checkbox"/> Nursing | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Health Administration | <input type="checkbox"/> Nutrition | |

Which category best describes you?

- | | | |
|---|---|---------------------------------------|
| <input type="checkbox"/> Student | <input type="checkbox"/> Paraprofessional | <input type="checkbox"/> DTR |
| <input type="checkbox"/> Person with a disability | <input type="checkbox"/> Policymaker | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Parent | <input type="checkbox"/> RD | |

Which of the following describes your place of employment or agency:

- | | | |
|---|--|---|
| <input type="checkbox"/> For profit agency | <input type="checkbox"/> General public | <input type="checkbox"/> Community organization |
| <input type="checkbox"/> County/ state agency | <input type="checkbox"/> Hospital | <input type="checkbox"/> Academic institution |
| <input type="checkbox"/> Federal agency | <input type="checkbox"/> Interagency group | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Foundation | <input type="checkbox"/> Legislative body | |

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Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services

Certificate of Attendance

Individual Copy

Continuing Professional Education
Certificate of Attendance

Nutrition for Children with Special Health Care Needs
Session Title: **Providing Family-Centered Services**


Participant Name

Date Completed

City, State

1
CPEs Awarded

II
Level

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State Copy

Continuing Professional Education
Certificate of Attendance

Nutrition for Children with Special Health Care Needs
Session Title **Providing Family-Centered Services**

Participant Name

Date Completed

City, State

1
CPEs Awarded

II
Level

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